

FASD ISN'T JUST ABOUT THE BRAIN!

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Declarations

- Kyle Sue:
 - No current relationships with any financial sponsors
 - Former contracted physician at Asante Centre
 - For developmental assessments
 - Site of my primary care program for people w/ Developmental Disabilities & families
- Allison Wong:
 - Executive Director of The Asante Centre

Asante Centre = FASD Society of BC
 Non-profit organization: advocacy and service

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Disclosure of Financial Support

- This program has NOT received direct financial support
- This program has NOT received in-kind support
- Potential for conflict(s) of interest:
 - Allison's salary comes from The Asante Centre (non-profit)
 - Kyle does FASD assessments as part of his work

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Mitigating Potential Bias

The FMF Committee has mitigated bias for this presentation as follows:

- Presenters agree to adhere to all Mainpro+ and National Standards
- Presenters have received the COI Quick Tips document
- Presenters agree to present only evidence-based content or declare otherwise
- Presenters agree to refrain from using brand names whenever possible
- Presenter agrees to include COI slides and verbal mention in each presentation

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Objectives

- Why is FASD an important topic?
- Debunk myths
 - *It's not just about the brain!*
- Barriers to health
- How to help?

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Prevalence



Conservative: 1.8%. Less Conservative: 4%. ^(1, 9)



660,000 - 1.4 million in Canada



Percentage of women of child-bearing age who consume alcohol?

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Prevalence

- Percentage of women of child-bearing age who consume alcohol? ⁽¹⁾
 - Answer: 75 - 80%
 - 58% binge drink between age 19-24 ⁽⁴⁾
 - 11% continue to drink after discovering pregnancy ⁽⁵⁾
- Unplanned pregnancies? ⁽⁴⁾
 - 50%
- How much alcohol exposure is needed?

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Prevalence

- How much alcohol exposure is needed? ⁽²⁾
 - Answer: A couple binge episodes of 4 drinks or more is enough. Or 7 standard drinks / week.
 - Less than that: results mixed, unclear
 - **No amount of alcohol is safe**

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What is FASD? - Knowledge still evolving!

- 1973: first described ⁽¹⁾
 - Constellation of effects from prenatal alcohol exposure
 - Congenital
 - **Lifelong**
 - 3 sentinel facial features (pathognomonic); ⁽²⁾
 - Short PF's
 - Flat philtrum
 - Thin upper lip
- Prevalence – **less than 10%** of ALL with FASD



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Canadian diagnostic criteria

Severe impairment in 3+/10 brain domains ⁽²⁾

- ▶ Motor skills
- ▶ Neuroanatomy/ Neurophysiology, e.g. microcephaly, seizures
- ▶ Cognition
- ▶ Language
- ▶ Academics
- ▶ Memory
- ▶ Attention
- ▶ Executive Function (inc. impulse control)
- ▶ Affect Regulation: e.g. MDD, Panic, GAD
- ▶ Adaptive Behaviour, Social Skills / Social Communication

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Animals vs. Humans



Animal studies: ⁽⁶⁾

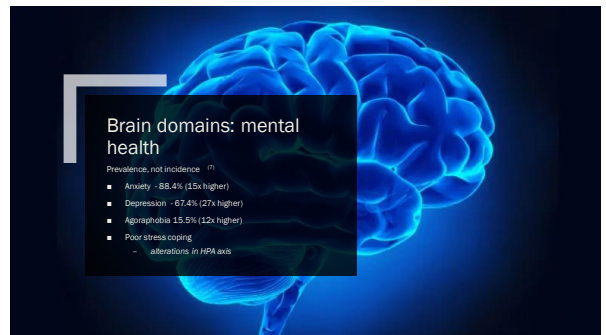
Prenatal alcohol affects growth and development in **most organs and tissues**.



Caveats/ confounders in humans:






e.g. high rates of complex trauma, low SES, poor living conditions, foster care, etc.

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Brain domains: mental health

-  Inattention / impulsivity - 87.4% ⁽⁷⁾
-  Cognition can be ID up to average or even high average
-  Adaptive functioning functional daily living skills often significantly lower than cognitive ⁽⁸⁾
-  Increased rates of substance use/abuse
-  Rates of criminal justice involvement: 60% within their lifetime ⁽⁹⁾

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Brain domains: sleep

Sleep disorders: ⁽⁷⁾

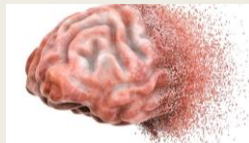
- Insomnia - 70%
- Frequent nocturnal awakenings - 57.6%
- Need to sleep during day (EDS) - 47.4%
- Night terrors & nightmares - 34%
- Night sweats - 24.7%
- Restless Leg Syndrome - 18.5%
- Sleep apnea (central & obstructive) - 15.2% (5x higher)

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Brain domains: seizures / dementia

- Seizures - 20.1% (20x higher) ⁽⁷⁾
- Dementia - 104x times higher (and early onset!)

In observational cohort study of 541 people with FASD, several had diagnosed dementia by their 40's to 50.



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Immune dysfunction

- Immune dysfunction / auto-immune disorders: ⁽⁷⁾
 - 29.5% with autoimmune disorder (vs. 5-8%)

e.g. lupus, sarcoidosis, celiac, rheumatoid, psoriasis, Crohn's, UC, Hashimoto's

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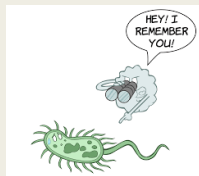
Immune dysfunction

- Asthma - 4x higher prevalence ⁽⁷⁾
- Allergies / Anaphylaxis
 - need for EpiPen - 4x higher prevalence

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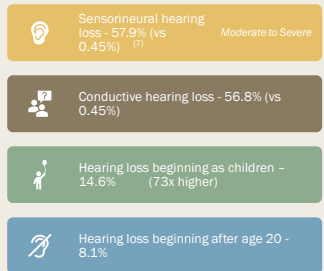
Infections

- Higher rates of recurrent ear and resp infections ⁽⁷⁾
 - Chronic sinusitis - 3x higher
 - Recurrent acute otitis media infections - 36.7% (147x higher)
 - Chronic serous otitis media - 77.3% (vs <1%)
(overlap with AOM stats above due to different study)
- Tympanostomy incidence - 22.2%
- Confounder:
 - Cleft lip and/or palate - 25x higher



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Hearing loss



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Endocrine dysfunction

- HPA axis ⁽⁷⁾
- Diabetes
 - Effects on structure/function of pancreas, increasing diabetic vulnerability
 - Higher rates
 - More likely to be hospitalized for treatments
- Non-diabetes related hypoglycemic episodes - 31.4%

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Endocrine dysfunction

Thyroid ⁽⁷⁾

Hypothyroidism -
5.6% (18x
higher)
Hyperthyroidism -
3x higher



Hyperparathyroidism - 3x higher

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Premature menopause - 7x higher

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Growth dysfunction

- Growth delay ⁽⁷⁾
 - 38% during childhood
 - Growth hormone levels?
- Unable to feel hunger - 36.6%
- Weight
 - Difficulty putting on weight - 21.5% (32x higher)
 - Higher rates of obesity also!

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GI dysfunction

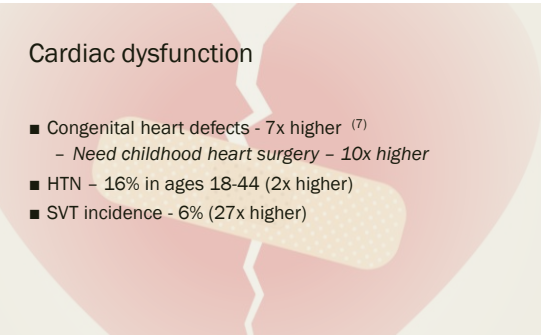


- Digestive issues ⁽⁷⁾
- GERD - 42%
- IBS - 20%
- Chronic constipation - 26.3%
- Chronic diarrhea - 13%
- Growth issues - is there contribution from malabsorption?

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Cardiac dysfunction


- Congenital heart defects - 7x higher ⁽⁷⁾
 - Need childhood heart surgery - 10x higher
- HTN - 16% in ages 18-44 (2x higher)
- SVT incidence - 6% (27x higher)



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MSK dysfunction

- Malformations of spine - 52.6% ⁽⁷⁾
 - Scoliosis - 9x higher
 - Fusion of neck vertebrae - 2% (8800x higher)
- Osteoarthritis - 4x higher
 - Higher prevalence and severity
 - Occurs earlier
- Gout - 8x higher
- Recurrent broken bones - 40.3% (multifactorial)
- Osteopenia before age 44 - 5.7%
- Osteoporosis before age 44 - 3.4%
- Adult hip dysplasia - 5%



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Peripheral nervous system dysfunction



- Highest prevalence of all ^(6,7)
- Electrophysiologic abnormalities of peripheral nerves - 91%
- Pain:
 - 86.7% with inappropriate pain sensation
 - Very high or very low pain tolerance
- Migraines - 33% (vs12-16%)

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Sensory dysfunction

- Easily overwhelmed by sensory input - 75.7% ⁽⁷⁾
- Can't tolerate loud noises - 63.4% (11.x higher)
- Texture sensitivities - 58.2%
- Can't tolerate bright lights - 57.5%
- Disordered sense of smell - 50.6%
 - Anosmia - 10.1% (9x higher)

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Visual dysfunction

- Visual impairment - 61.9% (7)
 - Congenital malformation of retina - 54.1%
- Amblyopia - 21.6% (11x higher)
- Nystagmus - 20.8%
- Strabismus - 11.4% (10x higher)

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Malignancy

- 
 Increased rates of some types of cancer (7)
 - 7 Immune related
- 
 Cancer history - 3% under age 45 (1.5x higher)
- 
 In observational cohort study of 541 males and females,
 - Cervical cancer diagnosed at ages 19, 24, 25, 27
 - Only measure - I don't have breakdown of that women enrolled

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Co-morbid syndromes

- Autism 15.1% (vs 2.24%) (7)
 - If this is the rate of autism in FASD, what is the rate of FASD in autism?
- Some kind of syndrome - 5%
 - e.g. Ehlers Danlos, neurofibromatosis, Prader Willi, Noonan's, Klinefelter's, Williams', etc.

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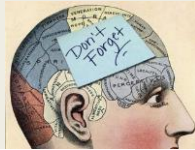
Barriers to health: language

- Less treatment adherence due to neurodevelopmental and social factors (7)
- Expressive and receptive language
 - Struggle to articulate symptoms, less likely to report concerns
 - Receptive deficits (difficulty understanding what's said) - 71.5% to 81.8%
 - Expressive deficits (difficulty expressing self to others) - 76.2%
- Literacy
 - Difficulty understanding what's read - 69%

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Barriers to health: executive function

- Executive function ⁽⁷⁾
 - Decision making difficulties - 85.8%
 - Judgment impairment - 82.8%
 - Organization
 - Working memory
 - Short-term memory - 81.5%
 - Long-term memory - 67.5%



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Barriers to health: stigma, social


Observational cohort study, 541 people with FASD ⁽⁷⁾


- median age 24, average age 27
 - 86% had a GP, similar to gen pop
 - 38% had a psychiatrist
 - 25% had a psychologist
- BUT
- Preconceived stigmas, social barriers in accessibility
 - Engage in less preventative care for early detection & follow-up
 - Access ED at higher rates
 - Complex needs not met in community


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Unanswered questions

- 

How many are medicated for psych issues when it's physical? Are we looking at the wrong thing?
- 

If sleep addressed, how many daytime problems can be attenuated?
- 

Chronic stress → Affecting health → Chronic stress How to break this cycle?
- 

How much disease burden in gen pop is undiagnosed FASD?
- 

If rates of illness this high in those with diagnosis who have access to healthcare, what is it like for those without?

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Quotes

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Patients feeling like they're not believed
- 

Referring to seeing a GP about her numerous medical problems: "Lol these and good luck going to a GP and getting all of these problems dealt with at once"
- 





Referring to telling a GP she had FASD: GP said: "Isn't that what you get when you're a baby?"
- 

Referring to telling a GP he had FASD when describing physical symptoms: GP said: "That's irrelevant."
- 

Referring to telling a new GP all his diagnoses: GP said: "That's not possible. You're too young."

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FASD = whole-body diagnosis

-  Issue of knowledge translation
-  Need a paradigm shift Not lazy, lying, sociopaths
-  Recognition of FASD as whole-body diagnosis Less emphasis on behaviour & mental health as all that is important
-  Early screening / higher suspicion Numerous conditions happening earlier & higher frequency

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How to help?


- Patients need supported healthcare & health decision making
 - Ask if it would be helpful to have someone else there to help support, take notes, etc.*
- Write down diagnoses & treatment plans
- Ensure understanding
- Be more lenient and understanding
 - E.g. missed appointments, disorganization*



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How to help?

- Need advocacy
 - Need increased access to funded adult FASD diagnostic assessments*
- For some, can make a diagnosis as a GP alone, without psychology and SLP.
 - Sorry. Talk for another day.*
 - Contact me for details.*



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Key Points

-  **FASD prevalence is high**
 Many go undiagnosed
 Morbidity is very high
-  **It's not just the brain - it's a whole-body diagnosis**
-  **Family doctors well positioned to lessen barriers to appropriately-informed non-judgmental healthcare**
 Including monitoring & early diagnosis / screening
 Small changes such as writing down diagnoses & management plans
 Advocacy

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References

1. CanFASD. (2019, July). "FASD basic information." <http://canfasd.ca/wp-content/uploads/sites/35/201907/FASD-Basic-Information.pdf>
2. Cook, J.L.; Green, C.R.; Lilley, C.M.; Anderson, S.M.; et al. (2016). "Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan." *CMAJ*, 188(3): 191-197.
3. Popova, S.; Lange, S.; Poznyak, V.; Chudley, A.E.; et al. (2019). "Population-based prevalence of fetal alcohol spectrum disorder in Canada." *BMC Public Health*, 19: 945.
4. Centre of Excellence for Women's Health. (2018). "Why do girls and women drink alcohol during pregnancy? Information for service providers." <http://cewhc.ca/wp-content/uploads/2018/04/Infographic-Alcohol-and-Pregnancy-English.pdf>
5. Denny, C.H.; Acero, C.S.; Naimi, T.S.; Kim, S.Y. (2019). "Consumption of alcohol beverages and binge drinking among pregnant women aged 18-44 years - United States, 2015-2017." *Morbidity and Mortality Weekly Report*, 68: 365-368.
6. Popova, S.; Lange, S.; Shield, K.; et al. (2016). "Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis." *Lancet*, [http://dx.doi.org/10.1016/S0140-6736\(15\)01345-8](http://dx.doi.org/10.1016/S0140-6736(15)01345-8).

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References

7. Himmelreich, M.; Lutke, C.; Travis, E. (2017). "The lay of the land: final results of a health survey of 500+ adults with diagnosed FASD." 7th International Conference on Fetal Alcohol Spectrum Disorder Research: Results and Relevance, UBC Interprofessional Continuing Education, Vancouver, BC. <http://interprofessional.ubc.ca/webcasts/fasd2017>
 - surveys in 25 areas a total of 260+ questions, 541 surveys done
 - community-based FASD groups, FASD diagnostic clinics, social service agencies within Canada and US
 - NOT random population sample
8. Flannigan, K.; Pei, J.; Stewart, M.; Johnson, A. (2018). "Fetal alcohol spectrum disorder and the criminal justice system: a systematic literature review." *International Journal of Law and Psychiatry*, 57: 42-52.
9. Tao, L.P.; Temple, V.; Casson, I.; Kirkpatrick, S.M.L. (2013). "Health watch table - fetal alcohol spectrum disorder (FASD)." http://bdprimarycare.surreyplace.ca/wp-content/uploads/2013/03/FWT_FASD.pdf

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Questions? Want to get involved?

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